



IPWSO

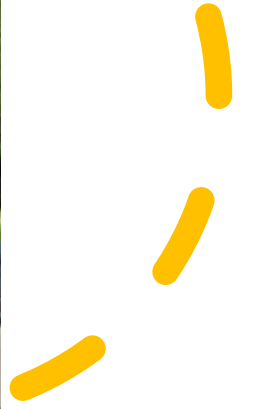
International
Prader-Willi Syndrome
Organisation



Decision-Making Capacity, Hyperphagia and PWS.

IPWSO, Caregivers Conference,
Berlin 2024
Gary Brennan

#PWSCARE24

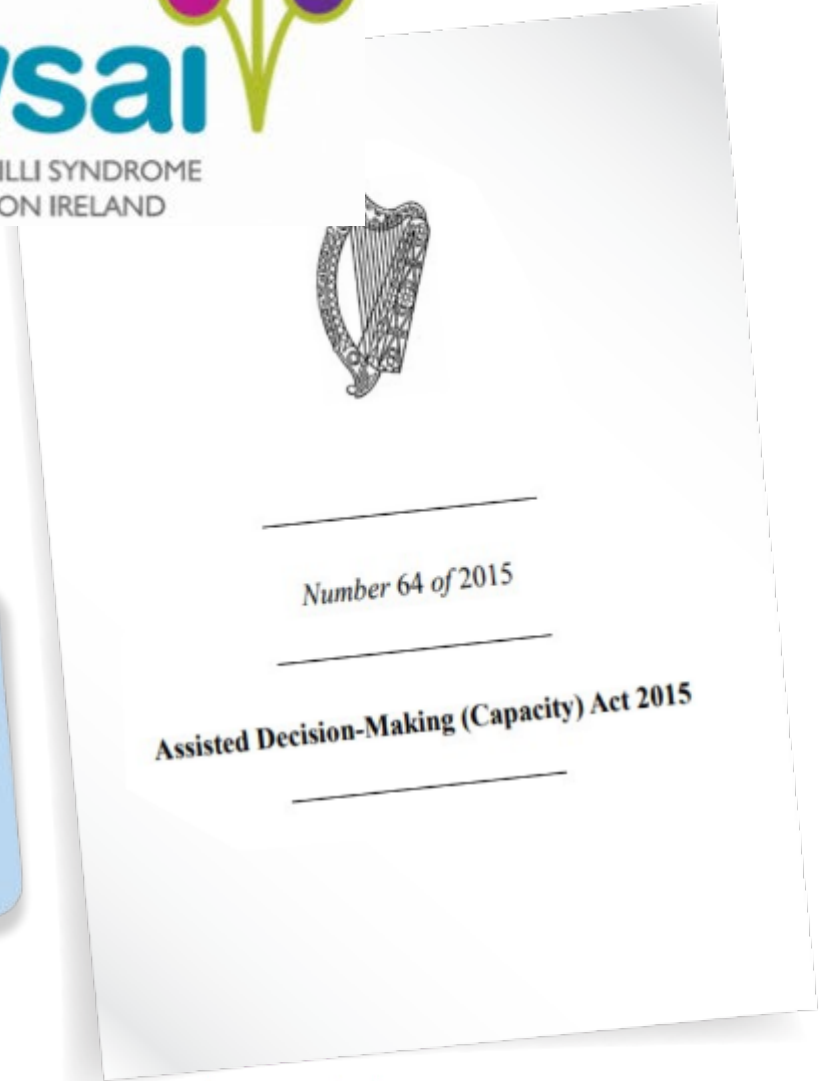




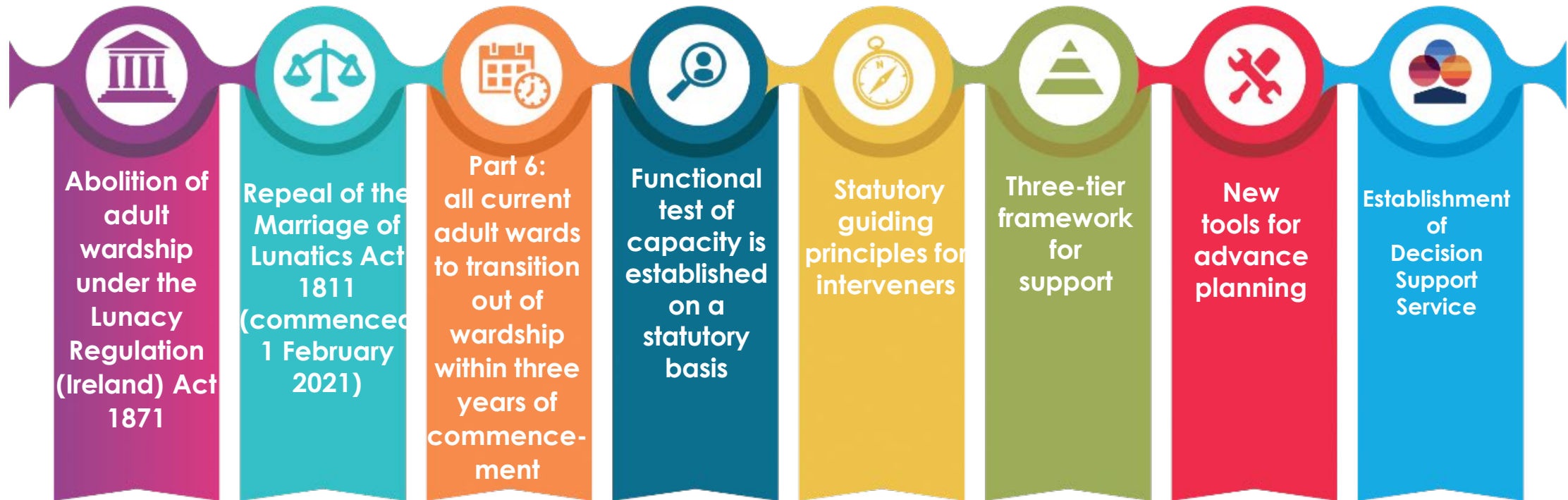
Assisted Decision-Making (Capacity) Act 2015

An Act to provide for the reform of the law relating to persons who require or may require assistance in exercising their decision-making capacity, whether immediately or in the future.

- Signed into law 30 December 2015
- Commencement 26 April 2023



Key reforms under the Assisted Decision-Making (Capacity) Act 2015



Who is the legislation for?

It applies to a person whose decision-making capacity is being called into question, may shortly be called into question, or lacks capacity, in respect of one or more than one matters.



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Moving to a human rights-centred approach

- The Act reforms the law in Ireland so that it conforms to the UNCRPD in relation to support a person to exercise their decision-making capacity to the greatest extent possible.
- It requires that every person is presumed to have capacity to make decisions about their life
- It centres the person in their own decision-making
- And requires that if a person is found to lack capacity to make a particular decision, their will and preference is respected and given effect to.



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What is capacity?

Capacity is defined as 'the person's **ability to understand**, at the **time** a decision is to be made, the **nature and consequences** of the decision to be made by him or her in the **context of the available choices** at that time'

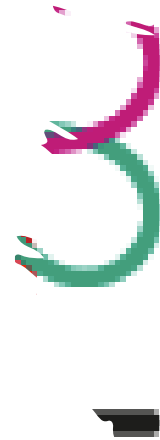


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What is consent?

“Consent is the giving of permission or agreement for an intervention, receipt or use of a health and social care service or participation in research following a process of communication about the proposed intervention”

(HSE National Consent Policy 2022)



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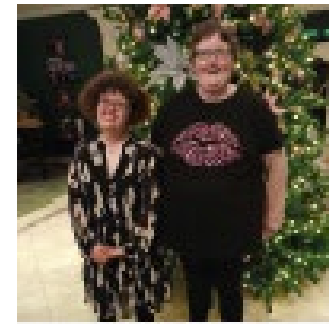
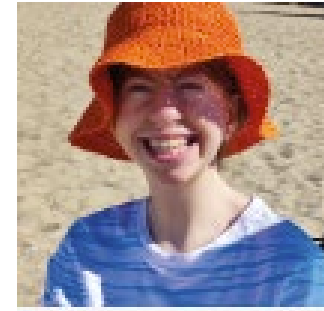


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1. Presumption of capacity
2. Support to make a decision
3. Unwise decisions
4. Accessible information
5. Legally recognised persons
6. Retention for short periods
7. Least restrictive intervention
8. Functional Approach to Capacity



Will and Preference

- A persons **will** is used to describe their long-term vision of what constitutes and 'good and fulfilling' life for them
- A persons **preference** means his or her greater liking for one alternative or another, over other alternatives which can be or have been demonstrated by words or behaviour or both.



'ke a dozen long-stemmer'

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3

Decision-Making Representative (DMR)

2

Co-Decision-Maker (CDM)

1

Decision-Making Assistant (DMA)



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National Office for Human Rights and Equality Policy



PWS and Decision-Making Capacity



Although people with PWS can make decisions about many areas of their life, dysfunction in areas of the brain that control eating behaviour and energy balance means that they will rarely have the capacity independently to make decisions about eating.

Number 64 of 2015
Assisted Decision-Making (Capacity) Act 2015

Deficit in Executive Functioning

- Core EF - Inhibition, response inhibition, self-control, resisting temptation, impulsivity, interference control, selective attention, and cognitive inhibition.



National Office for Human Rights and Equality Policy

Considering PWS and Decision Making

1. A malfunction of satiety consequent upon their genetic abnormality.
2. Feeding pathways are greater than that observed in those with typical obesity.
3. The consequence of uncontrolled access to food
4. People with PWS benefit from a food-controlled environment in ways that go beyond simply the prevention of obesity.



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Key elements for an effective supported decision-making methodology in service provision

To establish a supported decision-making methodology in service delivery, the following elements should be considered:

1. Following a person-centred planning approach.
2. Preserving the “dignity of risk” of each individual
3. Recognising and accepting the communication means of the person supported
4. Ensuring the continuous upskilling and reskilling of the workforce
5. Providing training opportunities and support to families of people with disabilities and staff working in mainstream services



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A Framework of Care

1. Crisis prevention should be prioritised
2. Provision of support should be based on individual needs.
3. Support should be planned collaboratively'
4. A more restrictive plan may be required to support the individual in crisis based upon their 'best interpretation' of the person with PWS's will and preferences and taking account of a least restrictive approach
5. Involuntary treatment that is not consistent with the person's will and preferences may sometimes be necessary to preserve life.

Murray A., Kuhn I., Gulati G., Fistein E., (2021) A scoping review of case law relating to support and treatment for people with Prader-Willi Syndrome, International Journal of Law and Psychiatry, Volume 78, <https://doi.org/10.1016/j.ijlp.2021.101733>.



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Our message to supporters in Ireland

1. Plan for the possibility of greater independence
2. Consider that in some cases this may mean managing access to food and monitoring the spending of money.
3. Choice is returned by reducing anxiety, which can undermine executive function
4. Ideally these strategies have the agreement of the person with PWS



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Further information

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